Rights Review

Promoting Human Rights by providing information and discussion across the DMR community

Newsletter of the DMR Human Rights Advisory Committee and the DMR Office for Human Rights

Volume 4 Issue 1 November 2005

Safeguarding the Rights of Individuals Subject to a Behavior Modification Plan

DMR regulations can be complicated and difficult to pull into a uniform voice when addressing more complex behavior challenges. The Strategic Planning Subcommittee on Behavioral Health Care empowered a representative group of DMR staff to provide guidance in clarifying safeguarding standards for behavior modification interventions. While there are several other modalities of treatment that may also be used to provide the most effective treatment and support to individuals in this population, behavior modification planning represents the most complex regulatory structure.

Safeguards are procedural protections and substantive standards delineated in DMR regulations to ensure that a person's rights are not unreasonably impinged. They form the due process rights of individuals receiving support from DMR. In general three important rights are safeguarded for individuals receiving treatment with a behavior plan:

1) the right to effective treatment to address issues that inhibit an individual's capacity to fully participate in their lives;
2) the right to personal liberty, including the right to be free from unwarranted restrictions of movement and other personal liberties; and
3) the right to have a voice in decisions that effect one's own life.

The rigor of these safeguards varies according to the level of intrusiveness or risk inherent in the planned intervention. The more risk involved, the greater the procedural protections.

Everyone has a role in safeguarding the rights of individuals. This includes the planning, implementation and monitoring of effective and humane behavioral treatment. This document provides guidance regarding appropriate actions established in the DMR regulations, policies and guidelines, for safeguarding the rights of all individuals receiving behavior treatment.

Level I Behavior Modification Plans:

Plans involving positive interventions only, or plans that pose a minimal degree of intrusion, restriction on movement, or risk of physical or emotional harm (see 115 CMR 5.14 (3) (b)), have the least safeguarding requirements. The sequential process of safeguards is as follows, though their practical application is not always in this order:

Included In This Issue:

1. To the degree possible, the person or persons best known by the individual, be they staff, guardian, family member or friend, should explain to the individual for whom a plan may be developed, the target behavior that limits the individual's participation and get their input. This will help develop insight into the needs and preferences of the individual and ensure that the individual understands the problem this behavior presents to the fullest extent possible.
2. The plan will be written by a clinician, experienced in behavior analysis (115 CMR 5.14 (4) (d) 2.), who will take into consideration information or insights relayed by the individual. The clinician will observe and get to know the individual in the environments in which interventions will be implemented. To the degree possible and appropriate, the clinician will explain the plan to the individual and give the individual an opportunity to have input into their treatment plan.
3. The plan will include a thorough behavioral analysis that informs the clinician of the role of the behavior, or why the individual is engaging in certain behavior, as required by 115 CMR 5.14 (2) "Behavior Modification."
4. If the plan includes any form of aversive stimuli, or deprivation procedures, including time out, it must include positive reinforcement procedures per 115 CMR 5.14 (4) (b) 4.
5. The service coordinator[1] has a critical role in safeguarding behavior planning and with proper supervision and support, will lead the team to ensure several aspects of good planning principles are in place:

a. That the plan is warranted and that less restrictive or intrusive interventions or support strategies have either been determined to be not effective to address the target behavior as required by 115 CMR 5.14 (b) (2) (or have been tried and failed).
b. The team has taken into consideration a comprehensive view of the individual's needs to rule out any physical, medical, environmental, or emotional issues that may be precipitating the target behaviors.
c. When other modalities of treatment are also used, sound clinical practice would dictate they be carefully integrated with the behavior modification plan.
d. Communication exists between all providers[2] of support to the individual, and any Level I plan is shared with all team members prior to implementation. The service coordinator ensures that the presence of the plan is documented in the person's ISP.
e. At least one person who understands the communication modalities used by the individual be responsible for explaining the plan at this stage to enhance the likelihood the communication will be successful so the individual has been consulted to the highest degree possible.
f. Consent, via whatever means necessary and appropriate to the circumstances, is voluntarily given by the word, or implied by the action of the individual, or their guardian. The individual or guardian had adequate information and sufficient understanding to comprehend the consequences of the decision (see 115 CMR 2.01 "Consent"). Consent will otherwise be obtained through support of the ISP by the individual and/or their guardian, if one exists, at the annual ISP review per 115 6.23 (5) c.
g. If the individual or guardian demonstrates or states their disapproval of the plan, a team meeting will be called to review the plan and consider amendment or elimination of the plan, per 115 CMR 6.25 (2) (d) and 6.25 (3) (a) and (b). The service coordinator may also assist the individual or guardian in understanding and upholding their appeal rights, per 115 CMR 6.31 (6). If the individual or their guardian believes the plan is more intrusive or aversive than allowed as a Level I Behavior Modification Plan, or is not being implemented according to the plan, they may appeal the ISP at any time (115 CMR 5.14 (5)).
h. The plan is monitored periodically, at least annually (115 CMR 5.14 (5) (b)), to ensure it is effective

[1] The term service coordinator should be understood to include Qualified Mental Retardation Professionals who perform the same function for persons in DMR operated facilities

[2] The term provider applies equally to private contracted provider agencies, DMR state operated community programs and DMR operated facilities

and still necessary. The individual, guardian or other team members may request a quarterly, or other time frame for review of the plan, under 115 CMR 6.24 (1). The treating clinician would be the logical source of the review information.

i. In a DMR operated facility Title XIX requires *any* individual program designed to manage inappropriate behavior be reviewed and approved by the Human Rights Committee for the facility (42 CFR 483.440 (f) (3) (i)). The federal regulations focus on whether the intervention implicates a persons human rights.

Level II Behavior Modification Plans:

Level II Behavior Modification Plans involve more than minimal degree of intrusion, restriction on movement, or risk of physical or emotional harm. In addition to the safeguards described for Level I plans, Level II plans require further safeguards because they involve interventions that may use physical force to overcome active resistance, significant physical exercise, application of unpleasant sensory stimuli, short delay of a meal, or a time out where an individual is placed in a room alone with the door closed (115CMR 5.14 (3) (c)).

These additional safeguarding measures include:

1. There will be a written informed consent specific to the behavior plan as finalized. It is not sufficient to accept written approval of the overall ISP as consent to the behavior plan per requirements of 115 CMR 5.08. It is recommended that the written consent for the Level II behavior plan will include the signature of a witness to the consent procedure. This will provide assurance that consent has been fully informed.
2. The service coordinator will ensure that the key team members are at the ISP modification meeting that reviews the plan, including, if possible, the clinician/s overseeing the development and implementation of the plan, and the individual and/or any guardian.
3. The service coordinator will ensure that prior to implementation, the provider agency has had the plan reviewed for medical contraindication of the interventions proposed for this individual by his or her physician or a qualified health care professional working under the physician's supervision, per 115 CMR 5.14 (4) (d) 4. The more obvious or significant the known medical needs of an individual, the sooner in the process this review should be completed. *This requirement is not waived when an agency head and treating clinician are working to implement the plan in an emergency.*
4. The Peer Review Committee (PRC) ensures that the clinical strategies embodied in the plan meet clinical, professional and regulatory standards. Except in an emergency, any comments of the PRC must be addressed by the treating clinician prior to implementation, per 115 CMR 5.14 (4) (d) 5.
5. The human rights committee (HRC) plays a critical role in safeguarding the rights of a person subject to a plan to ensure that the procedural protections and standards for planning have been upheld. The HRC is made up of volunteers who comprise a range of expertise, from family members, advocates and individuals receiving supports, to legal professionals, medical professionals and clinical/behavioral specialists. Their role is to ensure that safeguards are met and the interventions comport with community standards for reasonableness. The HRC reviews all Level II plans prior to implementation (115 CMR 5.14 (4) (d) 3.) and ensures:
   a. That the interventions are warranted and are the least intrusive or restrictive interventions available and effective for the individual.
   b. That the clinician has experience and training in applied behavior analysis and behavioral treatment.
   c. That a member or members of the committee have visited the locations where the plan will be implemented, so they may be familiar with that environment, the social context and the life circumstances of the individual.
   d. That if other treatment modalities are being used to respond to the same or similar behavior, sound clinical treatment would require that all treatment is coordinated.
   e. That a positive reinforcement program is in place to support the alternative or replacement behavior, whenever a restrictive or aversive intervention is being implemented to decelerate the targeted behavior.
   f. That any physical holding authorized under the plan is operationally defined and has a clearly articulated treatment purpose.
   g. That written and informed consent is adequate and complete.
   h. If the individual is unable to provide informed consent

and no permanent or temporary guardian has been appointed or is available, the HRC must ensure that the head of the provider agency has approved implementation of the plan, and concurrently acted to make a guardian available, per 115 CMR 5.14 (4) (e) 3. b.

i. That the intervention is ultimately reasonable in the eyes of the community. One role of the committee is to reflect the standards of the community in evaluating intrusions in people's lives. The diversity of its membership is intended to assist in representing the broad spectrum of opinion in the community.

j. That the dates when the plan as a whole should next be reviewed and when the data from the plan's implementation should be presented to the HRC are clearly specified.

k. That if the plan does not meet the regulatory requirements of 115 CMR 5.14, the plan shall not be implemented (per 115 CMR 5.14 (4) (d) 3. c.

l. That if the plan does not meet DMR regulations, the HRC may informally resolve the deficiency with the clinician so that needed treatment may be implemented, per 115 CMR 5.14 (4) (d) 3., c., i.

6. In the case where the HRC determines that the plan does not meet DMR regulations and no satisfactory resolution can be found, the treating clinician, individual, guardian or other representative, may appeal that decision in an ISP appeal, per 115 CMR 5.14 (4) (d) 3., c., ii.
7. Once both the PRC and HRC approve of the plan, the ISP team has agreed on the plan (which is technically a modification to the ISP), it must be submitted to the area or facility director and within ten days of the modification meeting, or decision to waive such a meeting (at the discretion of the service coordinator and with the documented support of the individual or their guardian, per 115 CMR 6.25 (5)), the area or facility director will approve or disapprove of the plan (modification). The appropriate parties then have the right to appeal per 115 CMR 6.25 (7).
8. In emergency situations the provider may develop and implement a behavior modification plan for an individual on a limited basis and under the following conditions:
   a. The treating clinician, with the concurrence of the program head, determines that the immediate application of the interventions provided for by the proposed plan is necessary to prevent serious harm to the individual or others, per 115 CMR 5.14 (4) (d) 3., 115 CMR 5.14 (4) (d) 5., and 115 CMR 6.25 (9).
   b. The program has obtained written and separate informed consent from the individual or guardian, if one exists, or on approval of the head of the provider if a guardian is needed but does not exist or exists but is not available and the head of the provider concurrently acts to make a guardian available, per 115 CMR 5.14 (4) (e).
   c. That a physician has determined that the interventions proposed are not medically contraindicated for that individual (115 CMR 5.14 (4) (d) 4).
   d. That the DMR area director or facility director shall be informed of the decision of the program director and the treating clinician to implement an emergency behavior plan by the service coordinator.
   e. That the treating clinician has 30 days from the date of implementation of an emergency intervention to receive approval from the PRC and the HRC (both of which may do an expedited review at the request of the program head) and file the plan with the ISP team for their consideration at an ISP modification meeting (115 CMR 6.25 (9).

Level III Behavior Modification Plans

Level III Behavior Modification Plans may include: contingent application of physical contact as an aversive intervention, time out where an individual is placed in a room alone with the door closed for longer than 15 minutes, an intervention that is highly intrusive and/or highly restrictive of freedom of movement, or any intervention which alone, or in combination with other interventions, or as a result of multiple applications of the same intervention, poses a significant risk of physical or psychological harm to an individual, per 115 CMR 5.14 (3) (d). The service coordinator, in conjunction with the ISP Team, the PRC, and the HRC for the provider, are all responsible for ensuring safeguarding standards are met. The Commissioner also plays a critical role with regard to the approval of Level III plans and providers. In addition to the safeguards required for Level I and Level II plans, the following standards must be met regarding the planning and implementation of Level III plans:

1. Any Level III interventions must be proposed by a program that has been certified by the

Department to implement such plans. These certifications are granted by the Commissioner after review by teams designated by the Commissioner, per 115 CMR 5.14 (4) (f).

2. Level III behavior modification interventions may be used only to address (115 CMR 114 (4) (b) 5.) "extraordinarily difficult or dangerous behavioral problems that significantly interfere with appropriate behavior and or the learning of appropriate and useful skills and that have seriously harmed or are likely to seriously harm the individual or others."
3. The Peer Review Committee may not include as a member of the Committee the clinician involved in writing and/or supervising the plan, per 115 CMR 5.14 (4) (d) 5., b.
4. If the person is seen as a competent individual, the program proposing the plan must inform the Commissioner that this is the case and show evidence that the individual has provided informed consent to treatment. The Commissioner, or their designee, may chose to have the individual evaluated for competency, per 115 CMR 5.14 (4) (e) 1. a.
5. If a person is not competent, a Level III intervention may not be implemented until a court of competent jurisdiction, using a substituted judgment criteria, has approved the interventions, per 115 CMR 5.14 (4) (e) 3. c.

Restrictive Strategies Not Incorporated Into Behavior Modification Plans

The ISP team that is coordinating the treatment planning and safeguarding the rights of an individual, should review any strategy or program that has a restrictive element that is not included in a behavior plan because it is not intended to modify behavior. Many of these plans are designed to keep an individual safe. The team should ensure that the strategy is warranted and not overly restrictive and document it in the ISP.

If any such strategy or program contains a limitation of movement, it must consistent with 115 CMR 2.01 "Limitation of movement" and be safeguarded under the provisions articulated for one of the five "reasons" found in this regulatory definition. This means it is either an emergency restraint, a support to achieve body alignment, a health related protection, a transportation restraint, or a behavior modification intervention. If a limitation of movement in such a program does not fit one of the reasons just stated, the program or strategy does not meet the due process standard found in the above definition. All limitations of movement must also be reviewed by the Human Rights Committee of the provider, per 115 CMR 3.09 (1) (b) 2.

If the program or strategy is not a behavior modification plan and involves limitations on possessions under 115 CMR 5.10 (1) or visitations per 115 CMR 5.04 (3), or restrictions of rights other than freedom of movement, not only should it be part of the ISP, but it should be reviewed by the Human Rights Committee of the provider program prior to implementation, to ensure its appropriateness. The review of safety strategies or programs to ensure that they are consistent with regulation, is an important role of the ISP team.

The principle of achieving well integrated, sound clinical care and supports would permit anyone with a formal role in the process, e.g. a representative of an HRC, an assigned member of the ISP team, etc., to be able to refer any question or concern they may have about this care to a DMR psychologist, or the Peer Review Committee that reviewed the plan, and expect a substantive answer to their question. Regulatory safeguarding questions from these individuals, or others, may be posed to the regional Human Rights Specialist, or DMR attorney.

Conclusion:

Everyone can play a role in safeguarding behavior planning. In addition to the above regulatory requirements, it is further recommended that behavioral treatment and management modalities of behavioral care be integrated into one document. Multiple plans, strategies and protocols that are designed to address the same or similar behavior should be documented in one plan. Such plans are sometimes described as "Coordinated Treatment Plans."

For clarification of the safeguards described in this document, contact the DMR regional Human Rights Specialist. If you are unclear about which specialist is assigned to you, please feel free to call 617-624-7738.

This article presented by a working group assigned by Deputy Commissioner Mark A. Fridovich, Ph.D., to compliment the work of the Behavioral Healthcare Strategic Planning Group. Participants included:
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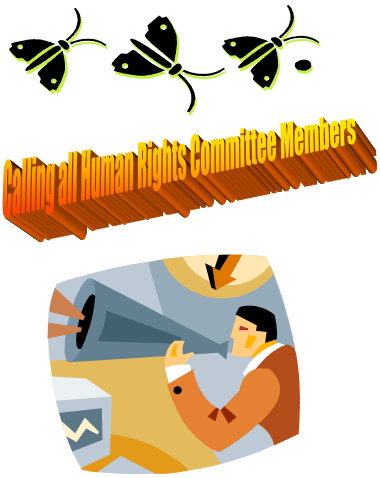
Susan Moriarty, then Human Rights Specialist, Central DMR;
Steve Nott, Service Coordinator, Worcester Area Office;
Veronica Wolfe, Risk Management Director, Northeast DMR;
Eric Alberti, Psychologist, Central/West DMR;
Delma Boyce, HRC Chairperson, Institute for Professional Practice;

Coordinated by Tom Anzer, DMR Director for Human Rights



By *Ana Diaz*, Human Rights Specialist, DMR Metro Region

FREE Human Rights educational resources are available to all Human Rights Committee members by Human Rights Specialists and DMR training offices statewide. We do more than provide free trainings and reference materials, by taking advantage of these educational trainings, you won't just be learning, you will be building confidence in what you do to safeguard the human and civil rights of the people we support. Human Rights Specialists are successfully helping Human Rights Committees with support and direction to achieve superior Human Rights knowledge by providing HR trainings, problem solving tools and networking opportunities.

Did you know that the Human Rights Officer/Coordinator training curriculum requirements have changed? It is now entitled Human Rights Systems Training. It is required for HROs and recommended for HRC members, direct support persons, HR Coordinators and administrators who play a role in supervising direct care staff or Officers. It is also useful for new Executive Directors to learn these roles.

In addition, there are some new offerings in each quarter and region that provide training on advanced human rights topics. These can be used to qualify HROs as having received continued human rights training, or benefit anyone involved in the system. Examples of these advanced trainings include: ***Behavior Modification Safeguarding, Safeguarding Liberty*** (Restraints and other Limitations of Movement), ***Recognizing and Preventing Abuse and Mistreatment, and Parties to a Complaint*** (the role of HRCs and others in Investigations and Incident Report Review), ***Processing Personal Restrictions*** (Visitation Rights, Possessions and Access Restrictions, ***Safeguarding Medication Treatment Plans***, and ***Restraint Authorizer*** training among others.

Wouldn't you agree that ***free*** HR training is hard to pass up? It is loaded with everything you need to help you along the way as you promote and protect the human and civil rights of the people supported by your agency. The DMR Office for Human Rights welcomes you to utilize our free training opportunities and maximize your skills as a Human Rights Committee member. DMR Training calendars are forwarded to all providers quarterly. Please inquire about the calendar at your agency, instructions are provided on how to sign-up for a training.

Knowledge is the word!

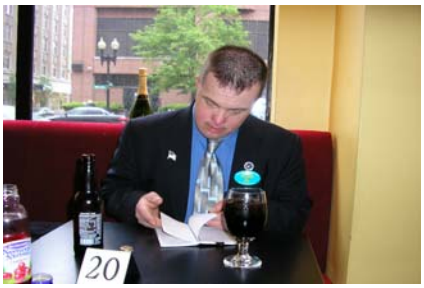
JOHN ANTON – LIVING THE DREAM

By Rich Santucci, Executive Director, Career Resources

When John Anton first became involved with Career Resources, we were asked to help support him at his job of bagging groceries. Though he had the skills to do the job, his behavior was creating havoc. John seemed more interested in pursuing his social interactions than in fulfilling the requirements of his job. John was also experiencing some difficulty in other areas of his life, which resulted in him giving up hi apartment, and moving back in with his Mother.

Things began to turn around for John a couple of years ago. John became very involved in the self-advocacy movement. Individuals who have developmental disabilities meet together for mutual support and to pursue legislative advocacy on issues that are important to them. John became more focused. He was able to move into an apartment with a roommate.

John began researching techniques for legislative advocacy on the internet. His friendly and open personality helped him in his meetings with other self advocates and legislators. John began to make presentations before groups. With the help of his support staff at the ARC of Northeast Essex County, he applied for and was awarded the Gopen Fellowship which would pay him $20,000 to work part time for one year to engage in a project of his choice in support of disabilities issues. He would be working out of an office hosted by ICI, the institute for Community Inclusion. The office is located on Park Plaza in downtown Boston.



John learned the difficult commute from Haverhill to

Boston, which includes a cab ride, the commuter rail, and the MBTA. He now makes this journey independently, with the support of a cell phone that he can use if he runs into anything unexpected.

John has traveled to Washington DC to meet with our Congressional delegation. He has made presentations to the a group of Special Education Instructors at the Downs Syndrome Congress, to Families Organizing for Change, students at University of Lowell, and members of the SEIU. He has been introduced at the State house to the entire House of Representatives. He has met with Governor Romney. He has had his picture in the Boston Globe in connection with his advocacy on the DMR name change. He is making two presentations at this Human Rights conference. He has picked up additional part time employment with the DMR's statewide quality council.
John has had this to say:
"I am working at my dream job"

"This job is keeping me more focused. I am working with my support team, not against them. I have come to realize that supporters are there to help me."

"I have always dreamed of having this type of job. I want to be doing advocacy on issues around disabilities. I have always wanted to be a professional."

John tells me that he has started writing a book called "the life of a professional". Writing a book is a tall order, but John has been doing things all of his life that seemed impossible. I wouldn't bet against him…

HRAC Wants You!

HRAC, the Human Rights Advisory Committee for the DMR is looking for a "few good issues" to focus our attention on in the coming year. As the Human Rights "eyes and ears" for the department, we are interested in emerging issues and trends which may impact the rights of individuals who we serve.

HRAC will be working closely with the myriad of other advisory groups and agencies that support the DMR in providing services to more than 32,000 people. We all want to insure that DMR services are provided in accord with the principles of transparency, fairness, and equal access, and in accordance with it's mission:

DMR is dedicated to creating, in partnership with others, innovative and genuine opportunities for individuals with mental retardation to participate fully and meaningfully in, and contribute to, their communities as valued members.

The DMR advisory groups include the following:

- SAC – Statewide Advisory Council, which supports the various citizen Advisory Boards
- Governors Commission on Mental Retardation
- DPPC advisory committee (disabled persons' protection commission)
- Quality Councils
- Family Support Council
- Health Care Advisory Committee
- Autism Spectrum Advisory Committee
- ADDP partnership committee (association of developmental disabilities providers)
- DMR Diversity council

HRAC will be meeting with representatives from these groups and will continue with our regular meetings with the department's own Human Rights Specialists from throughout the state. We will be gathering information about areas of concern and trends in the area of human rights. We will subsequently select two or three of the most important matters to focus on.

We would like to encourage you to call our attention to any concerns or subjects that you think are important, and that need to be focused on. We are particularly interested in hearing from Human Rights Committees.

Some of the areas that we have already identified for focus are:

- the new incident management system
- clinical safeguard in the area of the use of medication , particularly with respect to behavior modifying drugs
- the use of restraints
- proper training in the exercise of human rights for the individuals who we serve and their families
- the challenges of safeguarding human rights in community settings such as in shared living arrangements
- How to provide technical support for human rights committees to allow them to oversee clinical processes such as behavior plans and medication plans

Of course, HRAC will continue with our regular work. We will endeavor to provide technical support to the

human rights committees in the field, through our annual conference and through our newsletter. We will continue to advise the department and the commissioner on issues and concerns, through meetings and through our annual report.

This is certainly a full plate for HRAC, as a volunteer committee. However we believe that it is important. We also want to hear from you about issues that you think are important, that are emerging, and that need more attention. Please contact us.

From the Desk of the Director

Loss in the Community

By Tom Anzer, Director of the Office for Human Rights

With the falling of leaves this October, fell a strong advocate for persons with mental retardation. Delma Boyce was a member of the DMR Human Rights Advisory Committee and the chairperson of the HRC for the Institute for Professional Practice. Much more important to her, was her role as Dolly's mom.

Delma was driven by her love of her daughter Dolly and her desire for a good life for Dolly and all persons with mental retardation. She was affable, straight talking and always focused on outcomes for persons.

Delma passed away in mid-October, after a brief illness. She will be missed by all who knew her. She is survived by her daughter Dolly and her husband Jim, a member of the planning committee for the annual DMR human rights conference planning committee for the last several years.

Delma Boyce at 2001 Human Rights Conference, after co-delivering the keynote presentation.

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Editor's note: Each issue of the "Rights Review" is reviewed by DMR senior staff and represents the views and regulatory interpretations of the Department as a whole.

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Todd Kates, *Vice-Chair* (provider's executive director)
Delma Boyce, Secretary (provider HRC chair, family member)
Florence Finkel, Emeritus (Governor's Commission on MR)
Janice Feldman (Self-advocate, HRC Member, Glavin Regional Center)
Joana Johnson-Smith (family member, nurse)
Rita Fallon (On Leave)
Richard Santucci (provider's executive director)
Laurie Dupuis (provider's human rights coordinator)
Suzanne Choumitsky (provider's human rights director)
Tommy Stoddard (Psychologist)
John Thomas (advocate)
David Watson (lawyer, provider board member)

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http://www.mass.gov/ and find the DMR home page in the agency list.